

community worker). Lastly, we thank the patients, the lay health workers, farmers and the CMC health providers for sharing their information so generously.

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## Sociological and anthropological factors related to the community management of tuberculosis in the Western Cape communities of Ravensmead and Uitsig

J H P Ellis, N Beyers, D Bester, R P Gie, P R Donald

**Objective.** To determine the sociocultural understanding of tuberculosis among patients and their household members.

**Design.** Qualitative descriptive study.

**Setting.** Two adjacent Western Cape suburbs with a population of approximately 35 000, a tuberculosis incidence of > 1 000/100 000 and a surface area of 2.42 km<sup>2</sup>.

**Subjects.** Twenty-three adult patients on treatment for tuberculosis and their adult household members.

**Interventions.** None.

**Methodology.** Consecutive selected adult tuberculosis patients and their household members were interviewed with an open-ended interview schedule. General household and community conditions and non-verbal responses were recorded.

**Results.** There were relatively affluent but also severely deprived households with severe overcrowding. Substance abuse was common. Patients had limited understanding and knowledge about health, hygiene and the cause of tuberculosis. There was a perception of both physical and social distance between patients and health care providers. All patients relied exclusively on the conventional biomedical curative approach of the medical system to deal with tuberculosis.

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Department of Anthropology and Sociology, University of the Western Cape

J H P Ellis, PhD

Department of Paediatrics and Child Health, Tygerberg Hospital and University of Stellenbosch, Tygerberg, W Cape

N Beyers, MB ChB, FCP, MSc, PhD

D Bester, Nurs Dipl

R P Gie, MB ChB, FCP, MMed

P R Donald, MD



Conventional strategies to combat tuberculosis focus on the treatment of individual patients within the framework of a control programme.<sup>1,2</sup> This approach emphasises the role of education and behaviour adjustment on the part of patients, particularly with regard to compliance with a medical regimen. However, despite the availability of effective treatment regimens, exceptionally high rates of tuberculosis persist in the Western Cape, particularly among the coloured community.<sup>3</sup> The application of an exclusively biomedical model to the problem of tuberculosis therefore appears to be ineffective in combating and eradicating this disease.

Patients' experience of and presentation with illness on the one hand and professionals' diagnosis and treatment of disease on the other present potential and often real areas of conflict in health care treatment. They can also present an opportunity for negotiation of extended definitions of the respective clinical realities experienced by physicians and patients. What really is a separate 'popular' or 'sociomedical', as well as biomedical, clinical reality<sup>4,5</sup> may cause health care providers to focus only on the biomedical and clients to concentrate on the sociomedical aspect. It is possible for both parties to acquire some understanding of each other's model and to incorporate it into their approach.<sup>4</sup> Disease causation and treatment, including the problematic area of non-compliance, must therefore be understood by taking into account the social environment of patients, including living arrangements, belief systems, political and economic conditions and the nature of community health services.

This qualitative study was designed to determine, in a Western Cape suburb with a particularly high incidence of tuberculosis, the sociocultural understanding of sickness (and tuberculosis in particular) and the nature of a community in which tuberculosis is flourishing. The opportunity was also created for members of the community to state their own sickness experience and problems, including their understanding of the nature and causation of disease, attitudes towards treatment, service providers and ways of dealing with these experiences.

## Methodology

A sample of 30 consecutive pulmonary tuberculosis patients currently on treatment from the Cape Town suburbs of Ravensmead and Uitsig was selected from the case register of the local-authority tuberculosis clinic. These two adjacent suburbs have a population of approximately 35 000, a tuberculosis incidence of > 1 000/100 000 per year and a surface area of 2.42 km<sup>2</sup>. Details of demographics and family particulars were compiled and consent obtained for in-depth qualitative interviews with patients and other adult household members before the interviews were conducted. All 30 patients gave written informed consent for the interviews required for the study. It was made clear to each patient that a decision not to participate in the study would not prejudice the treatment of their tuberculosis in any way and that all information would be regarded as confidential. In 7 instances, after permission had been given, it proved impossible to arrive at a mutually acceptable time to

conduct the interviews. Therefore the final sample consisted of the remaining 23 households. Patients were all interviewed during the last 3 months of their therapy. Of the 23 patients interviewed, 5 were retreatment cases. Details of demographics and family particulars were compiled by a nursing sister who also arranged and obtained consent for the in-depth qualitative interviews with patients and other household members.

The qualitative data on belief systems, household and community practices, knowledge about tuberculosis and compliance, as well as service utilisation, were compiled through panel interviews with all the adult members of the selected households. In this way substantially more respondents than tuberculosis patients were interviewed. An open-ended interview schedule, containing the central elements and basic concepts to address the questions, was used. The schedule was developed by selecting items suggested by the literature on patient views of sickness and health and the specific literature on tuberculosis and compliance with medical regimens. These were then constructed as three broad analytical categories addressing demographic and family data, the sociomedical model of patients, and patient beliefs about and practices with regard to tuberculosis. The first contained sub-items including details of family composition and networks, socio-economic status, educational levels, religious and cultural beliefs, occupational status, residence patterns, quality of family life, family health, sexual attitudes and practices, substance use/abuse and community networks and support frameworks. The second category involved perceptions, cultural beliefs and views on health and sickness, views on practitioners and views on health care services. The final category contained subcategories on knowledge of and views on tuberculosis, the level of willingness to seek care, knowledge and views on medication, including items on how compliance is understood and defined, and on the treatment regimen with regard to convenience and behaviour change necessary, reactions to medication, views on the provider agency and, finally, involvement of and with supportive personal and community networks. These items therefore represented a checklist of questions to be asked during interviews based on the demographic data on household size, size of dwelling, educational levels, obtained beforehand, and the answers provided during the interviews, as well as the unobtrusive observations recorded as data thereafter. As a qualitative rather than empirical study, the content validity was developed not through pilot study but by refinement and sharpening of the questions and continuous analysis and interpretation of the data as the study progressed. Being open-ended categories, some items were ignored as respondents volunteered data or were elaborated on with further probing, dependent on the levels of understanding of different respondents. All interviews were tape-recorded and transcribed as field notes. Unobtrusive observations of respondents' non-verbal responses and general household conditions were recorded separately and incorporated into the field notes afterwards. The transcribed field notes, along with the written notes, were coded with basic concepts that provided the analytical categories for analysis of the data. The categories of data were grouped by codes and a continuous content analysis of the observation and interview data was made.



The study protocol was approved by the Ethics Committee of the Faculty of Medicine of the University of Stellenbosch and of the Departments of Anthropology and Sociology of the University of the Western Cape.

## Results

The baseline sample population included 15 male and 8 female current pulmonary tuberculosis patients with 10 patients (43%) aged < 30 years, 8 (35%) aged 31 - 50 years and 5 (22%) aged 56 - 63 years. Although the age distribution suggested that the population interviewed would be economically active, patients were typically unemployed and in all households evaluated, between 1 and 5 members were unemployed. Although household income data were not obtained, income was in most cases obviously meagre. The household size ranged from 2 to 18 (mean 8.7) and most respondents had a low level of education. No heads of household had an educational qualification higher than Standard 8. In 4 households, there were other household members, usually children, who had passed Standard 10 and, in 3 households, Standard 9.

### Demographic patterns of the sample respondents.

Both suburbs showed the usual difference between relatively more affluent and severely deprived households, with a very typical pattern of township overcrowding in the sub-economic housing areas. Some sections had dwellings with only two rooms, one of which doubled as a living room and bedroom, and the kitchen, which often served as a bedroom as well. High room occupancy was therefore a major feature in most households. In three cases homes with three bedrooms (with the living room utilised as one) had to accommodate 16, 17 and 18 people, respectively, and in one case a dwelling with two bedrooms was occupied by 14 people. The communities are fairly settled and most respondents have lived in the area for periods of up to 30 years. In cases where people have moved there recently, they came from other parts of the Cape metropolitan area. Some residents shared toilet facilities with an adjacent household and some complained bitterly about this, expressing what they sensed to be general insensitivity from local authorities about their plight. In a number of cases the homes were cockroach-infested, and household hygiene, judged from general appearance and upkeep, was poor. In some homes, especially where the living room doubled as a bedroom, the odour of urine and soiled bedding, and the smoke of paraffin used as fuel for cooking and lighting, hung heavily in the air, starkly underlining the poverty of the residents. The damp conditions of many homes with corrugated iron or asbestos roofing without ceilings contributed to the pervading sense of destitution. Often, however, the attempts of an obviously poor family to keep their home neat were impressive. Usually such family members displayed a more healthy approach to dealing with tuberculosis, especially with regard to compliance with medical recommendations. Alcohol abuse was often apparent when 1 or more members, often the patient, were intoxicated during interviews, and in 3 cases the respondents were heavily drugged with dagga. It was disturbing to conduct interviews when drunk respondents

often wanted to deal with issues not part of the interview or not in the power of the interviewer to deal with. The public hygiene, especially in some areas, was appalling. Refuse and junk lying around testify to poor public services and add to a general perception of malaise in the area.

**Perception of health.** Residents' overall perception of what constitutes health and how to remain healthy was extremely limited. While it varied with educational level, the most common responses were that being healthy means to 'feel good', to 'look after oneself', or to 'eat healthily' (which many respondents, given their poverty, obviously could not do). Quite often respondents defined health negatively: 'you are free from pain', 'if you're free from discomfort and worries'. One respondent alleged that 'many' tuberculosis patients in receipt of disability grants kept an account with shebeen owners who kept their payment authorisation letters as insurance for payment. She argued that this then resulted in many people's not having enough money to buy food for their families, who then scrounged off neighbours or depended on the philanthropy of people running occasional soup kitchens.

### Perceptions of personal and public hygiene.

Significantly, in the light of the shabby conditions of many homes, respondents' perceptions of the role of personal and public hygiene in maintaining health had to be probed. In some cases respondents commented at length about the 'inconsiderate neighbours' who promote unhealthy and unsanitary conditions as 'breeding places for germs'. Some respondents indicated a vague perception of the role of personal cleanliness, by referring to a need to be clean while their personal appearance was a clear contradiction of it. It appears as if, in some cases, very little education on personal and public hygiene principles and practices has occurred or been acted upon.

**Perceptions of sickness.** Perceptions of sickness were similarly limited and entailed broad views of personal neglect and a lay version of the 'germ theory'. With regard to the nature of tuberculosis this vague perception of a 'germ theory' was applied or reference was made to 'a spot on the lung'. Very few people had any real perception of the nature of the aetiology of tuberculosis and had various ideas about the role of sputum, sharing household utensils, cold and damp, smoking and working conditions that could have contributed to their sickness. Very little sense of the role of overcrowding, apart from 'breathing in the bad breath' of other sick people, or of other social and cultural factors, was found. A basic medicalised view was apparent, however, in response to questions about what to do when one is sick. All indicated that when sick one ought to, and that they would, go to doctors or use some prescribed or over-the-counter medicine. No one indicated reliance on or making use of any cultural practices, with only a few elderly people indicating that they do make use of traditional herbal remedies and that they believe in religion as a 'back-up' to medical care.

**Perceptions of compliance.** Very few patients indicated that they had stopped using the antituberculosis medication. We suspect that if they stopped at times they viewed this as wrong and were not willing to admit it. It was clear, though, that most of them had an understanding of the need to complete the course and often expressed their wish to be cured as a motivation for compliance. Some respondents



alleged that some other patients were non-compliant in order to remain sick and thus qualify for continual state social security support. This suggests understanding of the connection between compliance and successful outcomes, but also creative adjustment to situations of high unemployment and insufficient incomes. Nobody would readily admit to such abuse of benefits and questions about this prompted either denial or responses indicative of patients' incapacitation or the debilitating effects of the disease.

#### **Perceptions of treatment by professional providers.**

When asked about the treatment received from health care providers most expressed their belief in the scientific training and competence of providers. They described the treatment they received from personnel at clinics or the hospital as adequate, competent and sympathetic. However, a few patients from obviously very low socio-economic backgrounds expressed their dismay at what they perceived to be treatment from practitioners who seemed to want to place both physical and social distance between themselves and the patient.

**A specific sociomedical model.** The residents of Ravensmead and Uitsig are basically Western in their cultural perceptions and beliefs and therefore aware of and committed to the utilisation of biomedical resources. The majority of respondents' rather low educational levels, predominantly working class status and conditions of poverty, however, establish a wide social gap between them and almost all health care personnel. Most residents interviewed have rather poorly developed perceptions of the role of personal and public hygiene in the maintenance of health. Some respondents indicated a vague perception of the role of personal cleanliness, by referring to the need to be clean, suggesting very little education on personal and public hygiene principles and practices. Perceptions of sickness were similarly limited and their knowledge of the aetiology and pathogenesis of disease almost non-existent. A basic belief and trust in the professional medical system existed in all cases, making them rely exclusively on these services and this model of care. Their individualistic responses to their own conditions thus reinforce the conventional curative approach of the medical system in dealing with tuberculosis patients.

## **Discussion**

With so many patients incorporating a biomedical version of health and health care into their own sociomedical model, and the existence of an effective regimen for treating pulmonary tuberculosis, the continuing high incidence of tuberculosis remains perplexing. The results of the current study indicate that people have a lack of knowledge of the nature and causation of disease, particularly tuberculosis. Tuberculosis patients, especially, did not link relevant social, cultural and structural factors to their sickness conditions, even though they have some idea that the conditions under which they live are far from healthy. Respondents were, however, clearly informed about the medical regimen, and did not see it as problematic, difficult or too cumbersome to take or undesirable in its side-effects. Apart from the need

to walk to local clinics and the possible upset in a daily routine, particularly for a mother and housewife, most respondents indicated that they did not find the regimen troublesome. All patients also indicated that they understood the reasons and need for compliance, insisting that they wanted to be cured. Nonetheless, data from a very similar Western Cape community indicate that at least 32% of tuberculosis patients take less than 75% of their prescribed antituberculosis medication, despite the efforts of community health workers and the availability of a number of options for supervision of therapy.<sup>6</sup>

It is therefore clear that non-compliance is not the result of lack of knowledge of the medical regimen required to treat tuberculosis. People who live amidst the destitution often associated with tuberculosis may, however, not accord compliance with tuberculosis treatment a particularly high priority. Socially deviant factors such as unconventional use of benefits, alcohol and drug abuse, vagrancy and family violence may be prominent in their daily lives. Therefore, assessment also needs to take into account the financial, material, social and psychological situations, and the nature of the support systems in such destitute communities; how these influence choices that focus on immediate social needs and negatively affect health-seeking behaviour must then be evaluated. It is evident that the health team concerned in the management of tuberculosis, even when it contains members of the community, may not be sufficiently broad-based to accommodate the variety of problems associated with an epidemic of tuberculosis.

The study suggests that one should address problems related to the management and control of tuberculosis from a more comprehensive community viewpoint that would emphasise the stake all members of the community have in eradicating the disease. This means empowering the entire community, not merely through technical education about the sickness condition, but in a holistic manner that involves members as part of a team.<sup>7</sup> Tuberculosis thus becomes not only the concern of a single service provider (or even group of professionals) in contact with a single patient, but of an entire community that has an interest in the health of its residents.<sup>2</sup>

It is suggested that a team strategy<sup>8-13</sup> involving professionals, patients and community members be adopted to deal with this epidemic. This not only allows for a strategic management approach, but will complement the current effective one-on-one treatment regimen to effect optimum health outcomes in the community as a whole. The mere institutional arrangement that allows a number of professionals engaged in the care of tuberculosis patients to work together, usually in community clinics, should be viewed as a necessary though not a sufficient condition to establish (or refer to) a team.<sup>4,14,15</sup> The tuberculosis team should be a deliberately established unit with clearly formulated goals and objectives.<sup>8,11-14</sup> The team should include community members, nurses, physicians, microbiologists, social workers, anthropologists, sociologists, town planners, public health staff and construction experts.<sup>4,7</sup> Although the superior authority of medical professionals is often taken for granted,<sup>16-19</sup> it would, however, be advantageous to patient care if the team could operate as an egalitarian and collegial structure.<sup>4,10-13,15,20</sup> Professional autonomy of each individual can be maintained



through a clear definition of roles<sup>11-13</sup> and individual accountability in their own sphere of expertise and responsibility. Regular team conferences should be held where patient treatment and the overall objectives and strategies of the programme are discussed.<sup>4,15,21</sup>

It is essential that the team values be part of an ideology that includes a number of key operational principles.<sup>4,20</sup> These should include a focus on client and community needs (rather than a narrow focus on professional autonomy), egalitarianism, consensual decision-making and community orientation and involvement.<sup>2,4,10,13,15</sup> To support this a number of interaction strategies must be employed.<sup>22,23</sup> These include institutionalisation of the common ideology, rotation of team leadership, enhancement of communication skills, a communicative openness, a shared vocabulary and willingness to learn from one another, a non-parochial outlook, mutual respect for colleagues, informality and the use of humour.<sup>4,10-12,19,23,24</sup>

## Conclusion

Tuberculosis can only be cured if the individual sufferer is treated.<sup>2</sup> However, thousands of people still become infected and former patients develop multidrug-resistant strains. To suggest that the conventional tuberculosis regimen is not effective and should be terminated is unrealistic and courts disaster. However, the strategy should be extended by recognising its ramifications beyond mere 'biological factors'. Critical social scientists and health care consumers have saddled health care professionals with a dilemma. On the one hand, their perspective is criticised and they are urged to consider broader issues than just medical ones. On the other hand, they are admonished for trespassing on the lives of people or overstepping professional turf when they engage in 'medicalisation' of social life. The teamwork setting for dealing with tuberculosis provides the opportunity for scientific and clinical minds to focus on their own specialist areas, and for public health, construction, psychosocial and community experts to focus in detail on the patient as a total person and social being. But members have to give account of themselves to others, some outside of their area of expertise, and have to substantiate their evaluations and recommendations to them as they construct a common plan. In the process members may often traverse, yet not trespass on, the terrains of others who can now reinforce, challenge or modify findings and recommendations, a corrective mechanism that the individual professional with one client does not have. They have to rely on their own resources or have to refer their clients to another practitioner. The tuberculosis team will have the benefit of medicoscientific, psychosocial, public health, town planning and community minds operating together, and will then be able to transfer the responsibility of imparting the collective wisdom to the patients and the community by way of interpretive sessions and community conferences. In this way the team as a collective professional<sup>4</sup> solves the paradox and can provide humane medical care.

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